

Human Rights Resources for Families

4/25/2016



The Department of Developmental Services
Elin Howe – Commissioner
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Human Rights Advisory Committee
500 Harrison Ave
Boston Ma 02118



Introduction

In developing this resource material, we tried to look at the basic information that a family member would need in order to be an effective advocate. We have included some basic information about how the Department of Developmental Services provides services. We focused on common human rights concerns, with suggestions about how to advocate for positive outcomes. It is important to remember that individuals do not just receive services, they participate in them. This includes important decisions about what the services are and how they are to be provided.

The Department of Developmental Services

The Department of Developmental Services (DDS) is dedicated to creating, in cooperation with others, genuine opportunities for individuals with intellectual disabilities to participate fully and meaningfully as valued members of their communities

The service system

- DDS provides specialized services and supports to give individuals with intellectual disabilities the opportunities to live the way they choose.
- Service recipients include approximately 36,200 individuals with developmental disabilities.
- Service types include day supports, employment supports, residential supports, family supports, respite, and transportation.
- Services are provided through contracts with 235 private provider agencies.
- Once eligible for DDS services, each individual is assigned a service coordinator at their local area office
- Usually, the area office contracts with a provider agency to provide support services for which the individual is eligible to receive, and which are agreed upon by the area office, the provider and the individual/guardian. This is a partnership between the individual/guardian, the DDS, and the provider
- The provision of these services is monitored by a variety of sources within the department including area office staff, human rights staff, licensing staff, quality management staff, and investigation staff.
- Provider agencies are required to have human rights committees which provide oversight and monitoring.

DDS Commissioner and Central Office Staff



Human Rights

The Department of Developmental Services has a system of safeguards to affirm, promote and protect the human and civil rights of the individuals whom it supports. These rights include the basic U.S. Constitution's rights provided for all people. In addition to this, there are Massachusetts General Laws and DDS regulations which provide additional systems of safeguards to insure that individuals are free from mistreatment and are provided with opportunities for self-determination in their daily lives.

DDS System of Human Rights Safeguards

Every DDS and Provider Agency employee is responsible for treating each individual served with dignity and respect. They also must stop any abuse or mistreatment they witness, and are mandated to report such activity to the Disabled Persons' Protection Commission (DPPC).

Each Individual Service Plan (ISP) team includes the individual, guardian/family, their service coordinator, and provider agency staff. The ISP team determines the plan for services, including what will be provided and how they will be provided. This includes a review of any behavior support plan and restrictive procedures.

Human Rights Officers are appointed by Provider Agency Directors for each of their Agency service locations. These Officers are a point of contact for individuals and their families and can refer any human rights concerns/grievances to their agency Human Rights Committee.

A Human Rights Coordinator is an agency staff person assigned to provide oversight for the Provider Agency's Human Rights Officers, and to provide administrative support to the Provider Agency's Human Rights Committee.

The Human Rights Committee is an independent provider agency committee appointed in accordance with DDS regulations. These committees are charged protecting and affirming the rights of individuals, including the review and approval of behavior support plans, review of restraint orders, restrictive procedures, and investigations. They also provide advice to their agency director regarding the agency's policies and procedures.

DDS Human Rights Specialists are Regional staff members of the Office for Human Rights. They provide training, technical assistance and advocacy to all parts of the Provider and Departmental communities (including families, individuals, and human rights committees). The Human Rights Specialist assigned to each DDS Region is under the supervision of the Department of Developmental Services Director of Human Rights.

The Human Rights Advisory Committee (HRAC) represents all the constituencies of the Department and advises the **Commissioner** on significant human rights policies and concerns. HRAC ensures that individual rights are protected within the policies and practices of the Department.

<http://www.mass.gov/eohhs/gov/laws-regs/dds/> - This is a link to the full DDS regulations as well as DDS policies and other information, including OHR newsletters, background & updated or current Human Rights information etc.

Department of Developmental Services

Office for Human Rights

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500 Harrison Avenue

Boston, MA 02118

Phone: (617) 624-7738

| REGION | CONTACT INFORMATION | REGIONAL OFFICE/FACILITY |
|--------------|--|---|
| Central/West | <u>Teka Harris</u> Human Rights Specialist DDS Central/ West Region 140 High Street Springfield, MA 01105 Phone: (413) 205-0892 1-(800) 328-3123, x0892 | Central/West Region Berkshire, Franklin/Hampshire, Springfield/Westfield, Holyoke/Chicopee, South Valley (<i>Milford & Southbridge locations</i>), North Central, Worcester, Templeton Developmental Center |
| Northeast | <u>Rebecca Christie</u> Human Rights Specialist DDS Northeast Region Hogan Regional Center P.O. Box A Hathorne, MA 01937 Phone (978) 774-5000, x 528 | Northeast Region Lowell, Merrimac Valley, North Shore, Metro North, Central Middlesex & Hogan Regional Center |
| Southeast | <u>Nate Hoover</u> Human Rights Specialist DDS Southeast Region 151 Campanelli Drive, Suite B Middleboro, MA 02346 Phone: (508) 866-8916 | Southeast Region Brockton, Taunton/Attleboro, Fall River, New Bedford, Cape/Islands, Plymouth, South Coastal & Wrentham Developmental Center |
| Metro | <u>Jennifer Benoit</u> Human Rights Specialist DDS Metro Region 465 Waverly Oaks Road Suite 120 Waltham, MA 02452 Phone (781)788-5261 | Metro Region Newton/South Norfolk, Middlesex West, Charles River West, Greater Boston |



Behavior Support Plans and Restrictive Procedures

Individuals have rights to full access to their home, community, possessions and to have privacy. Under certain circumstances limitations may apply to these rights. This would only occur if the individual's safety and well-being are unreasonably jeopardized and if they &/or their guardian have consented to the limitation.

DDS Regulations state that:

Individuals have "... [t]he opportunity to undergo typical developmental experiences, even though such experiences may entail an element of risk; provided ... the individual's safety and well-being shall not be unreasonably jeopardized..." **Services should support Self-determination** & freedom of choice to the individual's fullest capability ... "*(DDS Regulations, 115, CMR 5.03)*

Sometimes providers may need to balance the individual's right to exercise self-determination with the requirement to insure the individual's safety and well-being.

Any restrictive procedure requires a formal consent and a review process which indicates:

- The proposed limitation is a response to an unreasonable health & welfare risk to the individual and others.
- The proposed limitation is the least restrictive intervention possible to maintain a reasonable safety measure.
- There is a teaching plan in place to reduce and/or eliminate a future need for the restriction
- There are specific criteria listed to fade or eliminate the restriction.
- The individual and/or their guardian have consented to the proposed restriction.
- The ISP team has reviewed the proposed restriction.
- The provider agency's human rights committee has reviewed the proposed restriction

Behavior support plans may be used to support the person in acquiring and maintaining those physical, mental, and social skills which enable the individual to cope most effectively with the demands of his or her own person and environment. A behavior support plan can be used when individuals have behaviors which put themselves or others at risk. A behavior support plan may also be used when individuals have behaviors which interfere with learning or with activities of daily life.

- The behavior support plan is considered to be "treatment"
- Sometimes the plan will include restrictive elements
- It must be the least restrictive method possible
- There must be data kept to determine whether the plan is effective
- There is a specific criteria to fade or eliminate the plan
- The individual and/or their guardian have consented to the proposed plan.
- The ISP team has reviewed the proposed plan.
- The provider agency's human rights committee has reviewed the proposed plan
- Some plans will require additional clinical review

What is informed consent?

Informed consent is **an agreement** voluntarily given by an individual or guardian who understands and weighs risks and benefits involved in a particular decision. As individual/guardian, you have the right to give (or withhold) your consent to treatments such as medications and medical procedures, behavior plans, and restrictive procedures; you also can withdraw your consent at any time.

What you, as Family/Guardian can do, if you feel an individual is restricted in an unauthorized manner:

- Contact your provider agency staff & **discuss** your concern. They may be able to resolve it immediately.
- Contact your service coordinator or your area office supporting the individual. They may **facilitate a helpful discussion** with you and the provider.
- Speak with the Agency's Human Rights Officer or coordinator. If necessary, you can **file a grievance** with the Provider's Human Rights Committee by contacting their Human Rights Officer or Human Rights Coordinator.
- Contact the DDS Regional Human Rights Specialist or DDS Director of Human Rights. They can **explain** the regulations and the review/approval process.

Notification of Incidents to You from your Provider

The provider agency is required to inform the individual and guardian of all incidents resulting in any of the following: physical injury that requires any medical treatment, emotional harm, significant property destruction, police involvement, suspected mistreatment of the person, or staff use of an emergency restraint on the individual. This notification should occur within 24 hours of the incident.

Speaking up for your family member

Advocating for Services You Want:

Each individual receiving DDS services has an annual Individual Service Plan (ISP) meeting, and you are part of the Team planning. The ISP meeting is very important for you for many reasons:

- **It allows** you as individual/guardian to share your vision for your life, which is the basis for the service plan and delivery.
- **It states** what services are currently provided and how they are carried out.
- **It reports** any assessment of the individual's abilities and needs, so the Team can make sure that ISP services address needs and expand abilities.
- **It provides** an opportunity for the individual or you to discuss concerns about current services As well as how they are provided. This is a good place to advocate for ISP changes you wish to happen.
- **It allows for changes** or additional services you want to happen.

Within 45 days of the ISP meeting you (the individual/guardian) will receive a written copy of the Service Plan to review, consent and sign. You have a right to consent or to appeal for changes. You may request Plan modification(s) before signing your consent. You should not wait until the next scheduled annual ISP meeting to

convey concerns or request changes. If you do not agree with the ISP or items in it, you have a right to appeal to your Regional DDS Director. Simply not signing the ISP doesn't constitute a rejection or appeal.

Expressing your DDS Quality Concerns & Rights to be Honored:

There may be instances, in which services are not provided as agreed to in the ISP, or do not comply with DDS regulations, or are just not satisfactory. Some people who receive DDS services cannot speak for themselves and need your help (as family, friend and advocate) to voice to their concerns.

All people have the following rights which you should know and advocate for if you feel they are not being honored and carried out:

Right to "humane and adequate care and treatment". Staff members should be attentive to your family member. They should speak to him/her respectfully, calmly, and in an age appropriate manner. Activities (such as television or music ...) should be based on individuals' interests rather than staff selection or preference.

Right to appropriate communication. Staff should assure that communication devices and other methods & modes of communication used by your family member are provided and used by all staff members.

Right to freedom from discomfort, distress, and deprivation which arise from an unresponsive and inhumane environment. Staff need to provide good and thorough personal care, so your family member is clean, comfortable and properly dressed. They should know the special support needs of each individual, which may include such things as communication method or device, specialized diet, medical &/or behavioral supports etc.

Right to self-determination and freedom of choice. This includes such things as deciding about what to eat and drink, how to spend their leisure time, when to go to bed, how to spend their money and so forth; to the extent possible, without exposing the individual to unreasonable risk.

Right to be visited and to visit others. There must be a compelling reason to limit these rights (such as safety of the individual and/or others); and such limit would require the individual's or guardian's consent, as well as a review by the provider's Human Rights Committee and the ISP team.

Right to reasonable expectation of privacy; such expectation includes assistance, whenever possible by same gender staff for personal hygiene and related needs.

Right to engage in activities that promote each individual's meaningful community integration. This includes any person needing staff support in the community. Program staffing levels should be sufficient to honor this right.

If your family member is not receiving the care they deserve, described in the Rights and DDS regulations above and agreed to in the ISP, you may need to help him/her speak up or speak up for them. To do so,

You can:

- **Contact** your Provider Agency's management staff &/or file a grievance with their Human Rights

Committee

- **Contact** DDS Area Office staff, including the Service Coordinator &/or Area Office management.
- **Contact** your Regional DDS Human Rights Specialist or the DDS Director of Human Rights
- **File your complaint** with the DPPC (Disabled Person's Protection Commission) or with the DDS Regional Senior Investigator, if you suspect abuse, mistreatment or neglect.

What to do if you suspect abuse or neglect by a caregiver

- **Call the DPPC** (Disabled Persons Protection Commission) **24-Hour hotline** at 1-800-426-9009.
- **The DPPC's mission is:** "To protect adults with disabilities from the abusive acts or omissions of their caregivers through investigation oversight, public awareness and prevention".
- **The standard for reporting** suspected abuse and neglect to the DPPC is "**reasonable cause to believe,**" which means that mandated reporters (legally responsible) need only "**suspect**" that abuse or neglect was committed against a person with a disability to report this incident. **Mandated reporters** must report suspected abuse and neglect; and, if they fail to do so, they are subject to a legal penalty. Most persons employed to work with individuals with disabilities are mandated reporters. **Non-mandated reporters** include individuals, family members, friends etc. who believe an abuse or neglect has been committed against an individual with disabilities, are also encouraged to report suspected abuse and neglect.

A person served by DDS, you, your family and friends or others may phone such a report to the DPPC hotline or file their complaint by filling out a DPPC abuse and neglect complaint form (located at www.mass.gov/dppc).

What happens next?

Once the DPPC receives the call or report, they decide if the information given meets their legal criteria to either screen the case "IN" or "OUT." To screen it IN, the information provided must suggest "**an act or omission of a caretaker resulting in serious physical or emotional injury, including consensual sexual activity**" has occurred.

- **The State Police review each case** to see if the allegation may be considered criminal conduct; if so, they refer it to the local District Attorney for review and possible criminal investigation.
- **When a case is "Screened IN"** & State Police have referred it criminally, on, DPPC staff may conduct an investigation under DPPC's statutory jurisdiction; or the DPPC may assign the case to DDS' Investigation Unit, where DDS investigators will pursue an investigation, but use the DPPC investigation standard.

- If a case is “**Screened OUT**”, it indicates the DPPC has determined that the information given does not meet DPPC’s statutory jurisdiction for a DPPC investigation.
- If “**Screened OUT**”, the DPPC may forward the case to DDS’ Investigations Unit, which has different criteria for their investigations. The DDS criteria for abuse and/or neglect include: “**mistreatment, acts which are illegal, dangerous or inhumane**”, but *not necessarily resulting in serious physical or emotional injury.*” If the case does meet that criteria, the DDS Investigations Unit will conduct their own investigation, using that criteria.
- If the alleged abuse or neglect does not rise to the DDS level of “mistreatment,” but still violates DDS’ **Program Standards**, the Investigations Unit may refer the case for a **DDS Administrative Review**.

Following notice of an Administrative Review, the Provider Agency *must take immediate action* to protect the health and well-being of the alleged victim, while waiting for the outcome of either an investigation or administrative review

<https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter19C> This link to Mass General Law chapter 19c, provides the legislative basis for the D.P.P.C. Section 4b, stating that the DPPC may refer cases to the DDS for investigation.

The Outcome of An Investigation or Administrative Review:

- A **redacted written report of the investigation’s outcome** will be sent to Individuals or their Guardians, upon their written request with instructions for appealing that outcome, in case they do not agree with it. The guardian would have to call DPPC to find out when the investigation is completed in order to make the request.
- The **provider agency’s human rights committee also receives a written report** of the outcome of the investigation and also have a right to appeal the outcome.

* **Two Disability Law Center Graphics** follow that provide a visual display of processes and options regarding stages of response to complaints of abuse or mistreatment within the Disabled Persons Protection Commission and the Department of Developmental Services.

How the Disabled Persons Protection Commission (DPPC) Handles Your Report of Abuse

Incidents of suspected abuse or neglect can be reported to DPPC through:

- A mandatory reporter (e.g.: most people employed to work with individuals with disabilities are mandatory reporters)
- Reports by persons who are not mandatory reporters (individuals may file official reports by filling out the forms located at: www.mass.gov/dppc)
- The DPPC hotline (DPPC's 24 hour hotline is: 1800-426-9009)

All relevant information is documented on a DPPC intake form, entered into a database and reviewed by DPPC Supervisory Staff.

A member of the State Police Detective Unit (SPDU) reviews all of the hotline reports and DPPC referrals for information that suggests a crime.

When criminal activity is suspected, it is reported by the SPDU to the District Attorney's Office for review and action.

Information entered into the DPPC database is reviewed to determine whether the incident meets the criteria for DPPC legal authority. The criteria are as follows:

1. the incident involves an individual with a disability between the ages of 18 and 59
2. it includes an act or omission by a caretaker
3. it results in serious physical or emotional injury.

If the report falls within DPPC's legal authority, an investigation begins. Investigators may be from DPPC or another state agency such as DDS, DMH, or MRC. Investigators will likely:

Visit the place where the abuse or neglect is alleged to have happened

Interview witnesses, alleged victim and perpetrator

Review documents

The investigator will submit a report to DPPC. This is technically due within 30 days, but often takes longer. The report may:

- Determine the nature, extent and cause of the injuries
- Identify the person(s) responsible
- Offer recommendations to eliminate risks for the person with a disability

If the report does not fall within DPPC's legal authority, the intake form is forwarded to the appropriate government agency for review.

To receive a copy of the completed investigation report, a written request must be submitted to DPPC's General Counsel using the Access to Records form at: www.mass.gov/dppc

To seek review of a DPPC investigation, an alleged victim, an alleged abuser or a state agency must file a completed Petition for Review form with DPPC within ten days of receipt of the completed investigation report to the Executive Director for DPPC. This request should specifically state the reasons for the petition. The Executive Director will render a final decision.

How the Department of Developmental Services (DDS) Handles Your Complaint

Any individual or human rights officer may file a complaint about a condition or incident that may constitute mistreatment and/or be illegal, dangerous, or inhumane by communicating the complaint to the Senior Investigator for the region. See www.mass.gov/dds for contact information for regional offices.

The complaint is immediately logged, and, within 3 days, a DDS Senior Investigator will determine the disposition of the complaint, which will be one of the following:

Dismiss the complaint if it is: frivolous; previously investigated with no new facts; and/or does not concern mistreatment or incidents or conditions that are illegal, dangerous or inhumane.

Refer the complaint to a Regional Director to resolve.

Assign the complaint to an Investigator.

Resolve the complaint immediately if necessary to protect the safety or welfare of the individual involved.

What will the Investigator do during the Investigative Process?

Hold private face-to-face interviews

Review relevant documents

Visit the site

What happens next?

Immediate protective action if required

Decision letter within 42 days

Prepare Action Plan

DDS distributes Action Plan and Decision Letter

What if you disagree with the Action Plan or Decision Letter?

- You may file a request for reconsideration with the Regional Director **within 5 days** after receiving the Action Plan.
- In your request, you must say why you think the Action Plan or Decision Letter is wrong.

How do you appeal?

- You may appeal if:
 - DDS denies your request for reconsideration OR
 - DDS reconsiders its decision but you still do not agree.
- You may file an appeal within 10 days after either of these events occurs.
- Within 30 days, the Commissioner will review all necessary documents, speak to the appropriate parties and write, date and distribute a final decision.

Resource List

- **Department of Developmental Services Office for Human Rights**
Richard Santucci, Director 617-624-7738
Rich.santucci@state.ma.us
- **Department of Developmental Services Website**
<http://www.mass.gov/eohhs/gov/departments/dds/>
- **DDS regulations and policies**
<http://www.mass.gov/eohhs/gov/laws-regs/dds/>
- **Disabled Persons Protection Commission**
<http://www.mass.gov/dppc/>
300 Granite Street Suite 404
Braintree, MA 02184
Phone: 617-727-6465
- **Disability Law Center**
<http://www.dlc-ma.org/>
11 Beacon Street, Suite 925
Boston, Massachusetts, 02108
Phone: (617) 723-8455 / (800)
- **Massachusetts Families Organizing for Change**
<http://www.mfofc.org/>
Massachusetts Families Organizing For Change
PO Box 61
Raynham, MA 02768
Phone: 508-824-6946
- **The ARC of Massachusetts**
<http://thearcofmass.org/>
PO Box 541603 Waltham, MA 02454
Phone: (781) 891-6270
- **Massachusetts Advocates Standing Strong**
<http://ma-advocates.org/>

(facebook page)
<https://www.facebook.com/Massachusetts-Advocates-Standing-Strong-231842356173/>
- **Massachusetts General Law chapter 19C - DPPC**
<https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter19C>
- **Disability info.org**
<https://www.disabilityinfo.org/>